

Operating Principles of the Public Health Data Standards Consortium

DRAFT

Name

The name of the organization shall be the Public Health Data Standards Consortium (PHDSC) and may be referred to hereinafter as the “Consortium” or the “PHDSC.”

Background

On November 2-3, 1998, the National Center for Health Statistics of the Centers for Disease Control and Prevention, in conjunction with the Agency for Healthcare Research and Quality and the National Committee on Vital and Health Statistics, convened a workshop to examine the implications of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) for the practice of public health and health services research. The workshop, “The Implications of HIPAA’s Administrative Simplification Provisions for Public Health and Health Services Research,” brought together 85 leaders in health statistics, research, and informatics to examine the challenges and opportunities presented by HIPAA.

Workshop participants developed consensus recommendations for establishing a consortium to organize the public health and the health services research communities on data standards issues. This consortium serves as a mechanism for ongoing representation of public health and of health services research interests in HIPAA implementation and other data standards setting processes.

What is the Consortium?

The Consortium is a coalition of organizations committed to the promotion of data standards for public health and for health services research through the collaboration of state, federal and private sector organizations. This involves using existing voluntary standards established by the standards development organizations and the data content committees, where applicable, and encouraging participation in the standards process where current standards do not meet public health needs.

The consortium is not an advisory body to the Department of Health and Human Services or any other governmental agencies regarding data standardization issues. Advice or recommendations to the Department of Health and Human Services can be provided by the individual member organizations, or groups of member organizations, or by the Consortium to the National Committee on Vital and Health Statistics, which is the advisory committee to the Department on health information policy.

Mission

The mission of the PHDSC is to improve the health and health care of the population through improved information by expanding involvement in existing health data standards and content organizations. The Consortium will facilitate the use of existing standards and the development of new data standards for public health and all areas of health services research. The Consortium will also help educate the public health and the

health services research communities about HIPAA and other health data standards issues.

Goals and Strategies

- Improve the health and health care of the population through improved information
- Convene local, state, and national health services research and public health entities around data standards issues, utilizing existing organizations to facilitate communication and disseminate information
- Identify high priority data needs that can be met through the HIPAA transaction and clinical standards, as well as other standards setting processes (e.g., ANSI X12 and HL7)
- Encourage participation and seek formal representation on data content committees (e.g., National Uniform Billing Committee and National Uniform Claim Committee)
- Educate the public health and health services research communities about standards issues
- Promote the efforts to assure continued access to health care information by public health and by health services researchers, with the appropriate safeguards for confidentiality of individually identifiable data

Membership

Consortium membership is open to any organization with a public health focus and with an interest in data standardization for the purposes of health services research and public health. These members may include: national public health data organizations, health services research organizations, federal and state public health agencies, managed care organizations, business coalitions and consumer groups.

Member Organizations currently include:

Agency for Healthcare Research and Quality (AHRQ)
Association for Health Services Research (AHSR)
Association of Public Health Laboratories (APHL)
Association of State and Territorial Health Officials (ASTHO)
California Office of Statewide Health Planning and Development (OSHPD)
CDC's National Center for Health Statistics (CDC/NCHS)
Centers for Disease Control and Prevention (CDC)
Center for Mental Health Services (CMHS)
Council of State and Territorial Epidemiologists (CSTE)
Health Care Financing Administration (HCFA)
Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
Massachusetts Health Data Consortium (MHDC)
Mental Health Statistics Improvement Program (MHSIP)
Minnesota Health Data Institute (MHDI)
National Association of County and City Health Officials (NACCHO)
National Association of Health Data Organizations (NAHDO)
National Association of Public Health Statistics and Information Systems (NAPHSIS)
National Association of State Alcohol and Drug Abuse Directors (NASADAD)
Nebraska Health and Human Services

New York Statewide Planning and Research Cooperative System (SPARCS)
Public Health Foundation (PHF)
Wisconsin Bureau of Health Information

Additional Organizations invited to join the consortium are:

American Hospital Association (AHA)
American Medical Association (AMA)
Association of Maternal and Child Health Programs (AMCHP)
California Cancer Registry
Health Resources and Services Administration (HRSA)
National Academy for State Health Policy (NASHP)
National Association of State Medicaid Directors (NASMD)
National Committee for Quality Assurance (NCQA)
Substance Abuse and Mental Health Services Administration (SAMHSA)
Utah Health Information Network (UHIN)
Workgroup for the Computerization of Behavioral Health and Human Services Records

Member Organizations' Roles and Responsibilities

- Designate Consortium Steering Committee member and alternate.
- Participate in all Consortium meetings and conference calls.
- Disseminate information regarding Consortium activities to its members.
- Solicit feedback from its members on any Consortium business and necessary issues.
- Promote the activities of the Consortium at any of its meetings as feasible.
- Subscribe to the Consortium listserv and participate in listserv discussions regarding issues of data standardization for health services research and public health.
- Participate in discussions and decision-making regarding Consortium workplan and projects and be involved in consortium activities as able and as necessary.
- Represent Consortium proposals at the appropriate data standards organization or data content committee.
- Identify other members of the respective organization to work on Consortium projects, work groups, etc.

Steering Committee

The Steering Committee will include one representative and an alternate from each organization, who will facilitate the above roles and responsibilities for their respective organization.

Planning Group

The Planning Group for the Consortium will consist of up to ten individuals selected annually by the Steering Committee and will include the federal and state representatives of the Consortium to both the National Uniform Billing Committee and the National Uniform Claim Committee. This Group will perform the administrative functions of the Consortium such as: scheduling and planning meetings, seeking out and assuring budgetary resources, keeping consortium records including all meeting minutes, and maintaining the Consortium website and listserv.

Standing Work Groups

The Consortium Steering Committee may establish Standing Work Groups to be responsible for projects that the Steering Committee determines would address on-going and dynamic issues in data standardization. A Standing Work Group may include members of any Consortium member organization. Standing Work Groups will be permanent entities of the Consortium until otherwise determined by the Steering Committee.

Ad Hoc Work Groups

Ad hoc workgroups may be created to assume responsibility for coordination and implementation of any project approved by the Consortium Steering Committee. Any member of a Consortium member organization can serve as either member or chair of an ad hoc work group. An Ad Hoc workgroup will cease to exist when its work has been completed and it has submitted a final report to the Consortium Steering Committee.

Discussion and Decision Making

All members will work together to define problems and generate options to reach decisions by consensus. All members will work toward a common understanding and agreement that satisfies all interests. This involves discussions to explore all interests and needs in an effort to reach a mutually acceptable agreement.

This consensus process is meant to:

- Establish an open and creative atmosphere;
- Ensure effective participation;
- Honor the perspective of all participants;
- Encourage and recognize the different perspectives in a group;
- Resolve disputes;
- Maintain Consortium focus, balance and purpose; and
- Get positive results.

Consensus is established when, in the judgment of the Steering Committee, substantial agreement has been reached. Substantial agreement means more than a simple majority, but not necessarily unanimity. All views and objections will be considered and an effort made toward their resolution.

Voting

Voting can occur at any meeting of the Steering Committee or at any broader Consortium meeting. Each member organization is allowed one vote, either by that organization's representative or the alternate. Voting may also occur by electronic mail.

Funding

To the extent possible, member organizations will bear the cost of participation in the Consortium.

Meetings

The Consortium shall meet at such time and place as is determined by the Steering Committee. The form of such meetings may be face-to-face or by teleconference as deemed appropriate. Consortium meetings may also be scheduled as an adjunct to the annual meeting of one of its member organizations. Meeting times will be no less than annually. Members will receive advanced notice.

Quorum

A quorum for purpose of conducting the business of the Consortium shall consist of representatives of the majority of the Steering Committee member organizations.

Minutes

Minutes of each meeting will be prepared and published on the Consortium website.

Communication

As a medium for information dissemination and for the discussion of data standards issues, the Consortium has established a listserv called the PH-CONSORTIUM-L. Subscription to this listserv is not restricted to member organizations but is open to anyone who wishes to participate. To subscribe, the individual must submit a request to listserv@list.nih.gov with the following in the body of the letter: subscribe ph-consortium-l *your name*. Access to the listserv is also available on the internet at <http://list.nih.gov>.

The Consortium website is www.cdc.gov/nchs/otheract/phdsc/phdsc.htm.

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